

# My Journey to a Good Night's Sleep

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by nasal cannula) will do nothing to inflate the balloon. ■

## References

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When I was 5 years old, I contracted polio. The family doctor, summoned to my home, carried me out the front door. I have not retained much of the following weeks and months except that my parents were kept away from me, and, at some point, I felt that I was suffocating. I was placed in an iron lung, but do not remember how long. Rather than being sent to a rehabilitation facility, I returned home and had visits from a physical therapist. I had leg braces, a strange arm brace that held my right arm straight out from my shoulder and bent at the elbow, and a little wheelchair.

I did not attend school until third grade, and by that time I had tossed the braces and wheelchair. Breathing did not seem to be an issue then. At age 8, I had a spinal fusion and was out of school for fourth grade. Back in school for fifth grade, I used a wheelchair for trips to the playground where the other children used me as a battering ram.

Around this time, I remember having difficulty coughing up secretions when I had respiratory infections. I remember being embarrassed in class while trying to cough, terrified that I would choke to death. Years later, I figured out that shoving

myself on my abdomen could help while trying to cough. I still use that same method.

In the early '80s, I attended a GINI conference in Saint Louis. There was a lot of talk about breathing problems and respiratory infections. I remember Augusta Alba, MD, mentioning the possibility of "drowning in your secretions" and the necessity of dealing with this aspect of the late effects of polio. One of the vendors had a chest shell breathing device that I tried. Someone nearby said, "You should have seen the look on your face when you tried that thing." So that is what it felt like to breathe!

Back home in California, I tried

to track down information about breathing devices and how to deal with respiratory infections – without much luck. One pulmonary doctor told me that, because I had not died during the initial attack of polio and no longer used the iron lung, I could not have breathing problems related to polio. I did not believe him, but did not feel in serious trouble except when I caught a cold.

Then came nightmares of drowning or suffocating, waking up choking, morning headaches, and, worst of all, getting up and down many times during



CONTINUED ON PAGE 10

the night to use the bathroom. I eventually went to another pulmonologist who sent me home with a pulse oximeter. I was also referred for a pulmonary function test that was only done in a sitting position, not repeated while lying on my back (supine). Based on the results of these tests, I was provided with a bi-level positive airway pressure device and a mask. I tried it for a few nights, but it was awful.

About five years ago, a respiratory therapist friend encouraged and helped me to get an appointment with a doctor at Kaiser's regional rehabilitation facility in Vallejo, California. I had pulmonary function tests and was referred to the overnight sleep lab. After two hours, the lab technician came into my room and said, "You're not breathing enough." She gave me nasal pillows to use with a bilevel device. For a few minutes I thought I would surely suffocate and die, but the technician was very comforting and managed to calm me down. Eventually, I fell asleep.

My new doctor prescribed a Bi-PAP®. Since my insurance policy does not cover durable medical equipment, I paid for these items myself. I was sold nasal pillows, headgear, and tubing to attach to the machine that I rented for a month. There was no mention of other brands or models that might exist. When I began using the new equipment, I hated it. The machine was noisy, I heard the air coming in with every breath, and I felt the air as it shot each breath at me. The nasal pillows leaked and my nostrils were sore in the morning.

I tried to educate myself about the whole situation and found a polio chat room where breathing issues were rarely discussed, except once when someone mentioned a breathing machine that was quieter than others. So, there were choices out there. I would not have to settle for the first machine I tried.

Over the next couple of months, I rented about five different machines and tried a variety of masks (interfaces). My husband, Roger, assembled files of information and phoned vendors and manufacturers to learn what was available and what each might cost. Roger and I get similarly possessed when we are in the market for a new washing machine or a new variety of tomato for the garden. But in a serious medical situation, should it have to be do-it-yourself? There is no equivalent to *Consumer Reports* to provide a thorough, unbiased comparison of ventilatory equipment.

When it came time to quit testing machines and buy one, I settled on the Quantum® Pressure Support (no longer being manufactured). It was the biggest, heaviest, most expensive one I had tried. But the adjustable rise time sold me. Each inspiratory breath is delivered gradually. This is essential for my comfort. I also liked the controls on the Quantum. They are located on the front and are easily adjustable when necessary. There are no secret adjustment codes available only to "professionals." The Quantum can also be set with a backup rate for timed breaths, a feature I use. With some of the machines I rented, my spontaneous inhalations

were apparently not always strong enough to trigger the machines to give me a breath.

Next, I wanted a smaller, lighter-weight unit for backup and for traveling, and found the Sullivan VPAP® II ST which has adjustable rise times and can be set to my specifications. I now use the VPAP exclusively and keep the hulking Quantum as backup.

At journey's end, I now go to sleep within a few minutes of going to bed. I have no more morning headaches. I have not drowned nor suffocated in a nightmare. Best of all, I no longer need to get up to go to the bathroom during the night. (According to Colin Sullivan, BSc Med, MB, BS, PhD, FRACP, FAA, from Australia, who helped develop the VPAP, there is a biochemical chain reaction that may result in nocturnal urination when people are underventilating during sleep.)

While waiting to discover the ideal mask, I use a ResMed Mirage® and Ultra Mirage®, liking different features of each. I also use a heated, homemade humidifier and so far have resisted spending hundreds of dollars on a "real" one. Use of a humidifier was not mentioned when I bought either of my machines, and I found that dry air being blown into the nose and throat could be uncomfortable.

I located mail-order companies selling equipment and supplies on the Internet. The prices are often better than buying through a local respiratory equipment dealer. For repeat orders of supplies that I know will work, this can be a savings. ❧